Public education about normal forgetfulness and dementia

PUBLIC EDUCATION ABOUT NORMAL FORGETFULNESS AND DEMENTIA: EFFECTIVENESS OF A SYSTEMATICALLY DEVELOPED INFORMATION BROCHURE

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Earlier research revealed that many elderly people in The Netherlands are worried about their forgetfulness and are afraid of incipient dementia. Until now, no systematic research has been conducted on the effects of public education about normal forgetfulness and dementia, and therefore an information brochure was developed and evaluated. The main function of this brochure was to reassure people who were unnecessarily worrying about possible dementia. A second function was to motivate people to seek professional help when this seemed advisable. Sixty-two percent of all respondents (307 of 400) who had been worried about dementia before reading the brochure said that their anxiety decreased or disappeared after reading it; approximately 3% became more worried after reading the brochure. A cognitive test battery was administered to 104 people to determine whether their increased or decreased anxiety was justified. Thirty subjects had low test scores, yet 16 of these subjects had been reassured by the brochure that their forgetfulness was nothing to worry about. This group was characterized as experiencing fewer problems in daily life as a result of their forgetfulness and as having a higher internal locus of control. Seventy-four subjects performed well on the cognitive tests, yet 18 of them had remained worried about their forgetfulness after reading the brochure. Anxiety for heredity of dementia could be a possible explanation for their persistent concern. Although many people were reassured by the brochure, the results also show that it is important to evaluate information brochures used as intervention instruments—in one third of the present sample, the effects of the brochure were not in accordance with its goal.

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The prevalence of complaints about memory and forgetfulness increases with advancing age. Recently, it was shown that about 50% of 350 elderly people who attended an information meeting entitled "Forgetfulness: Often a Normal Phenomenon" were very worried about their memory (Commissaris, Verhey, Ponds, Jolles, & Kok, 1994). More than half of those who complained about memory loss (56%) were also afraid of incipient dementia. The existing lack of sufficient information about the difference between normal forgetfulness and dementia is one of the main causes of misunderstanding and prejudice among the general public. For example, many people think that forgetfulness in elderly people always results in dementia (Commissaris et al., 1994).

An extensive search of the scientific literature revealed that only a limited number of articles exist on the topic of education about memory problems and dementia. No publications exist about education for people who worry about their forgetfulness or education for health care workers or the general public. This does not necessarily mean that there is no education or information available for these three target groups, only that there has been no systematic evaluation of education activities. Publications about education activities for caregivers of dementia patients were found in the literature, but the information that was provided was mainly integrated into skills training programs for the care of a demented family member (Gendron et al., 1986; Meier-Robinson, 1988; Teursink & Mahler, 1984). The spouses and social environment of dementia patients receive little information from physicians about the disease and the problems that might occur (Chenoweth & Spencer, 1986; George & Gwyther, 1986; Haley, Clair, & Saulsberry, 1992; Commissaris et al., 1995).

Because of the existing misunderstanding and the lack of adequate information, it is worth paying more attention to education programs about memory, normal forgetfulness, and dementia. These programs require careful planning, because it is necessary to have insight into the characteristics, level of knowledge, and existing needs of the target group (Kok, 1992). Current education activities seem to take place mainly on an ad hoc basis, usually as a result of the existing need of a group of elderly people or of professionals who have a lot of contact with elderly people.

At the request of the Dutch Alzheimer's Association, we developed a brochure to fill the gap and meet the current information need. This brochure, entitled "Forgetfulness or Dementia?", was developed in accordance with current procedures in health education research (Green & Kreuter, 1991). An important condition for a successful health education intervention is careful and systematic planning (Mullen, Green,

& Persinger, 1985). In this case, a brochure was used in order to reach a large group in a relatively inexpensive way.

The brochure is meant for elderly people who are worried about their forgetfulness or about dementia and for health care professionals (e.g., general practitioners and district nurses). Before the brochure was distributed nationally in April 1992, we investigated its effectiveness with a small group of elderly subjects in the province of Limburg. Our first goal was to measure the effects of the brochure on all 463 respondents who cooperated, taking several independent variables into consideration. Our second goal was to find out whether possible changes caused by the brochure were in the right direction. In other words, did the brochure eliminate or decrease anxiety in people who were worrying unnecessarily, without producing "false positives" or "false negatives"? Did the brochure convince people to seek professional help when this seemed advisable? We investigated the direction of changes in a subgroup of 104 of the 463 people by using a short cognitive test battery.

THE INFORMATION BROCHURE

The first version of the brochure was developed in 1991 by the staff of the Maastricht Memory Clinic (Verhey et al., 1993) and other experts. The text is based on scientific knowledge regarding age-associated cognitive functioning, on the questions asked by patients of the clinic, and on experience gained from information meetings about normal forgetfulness (Commissaris et al., 1994). The text was carefully checked against educational criteria (Green & Kreuter, 1991) and presented to 5 people from the target group. It was adjusted where necessary on the basis of their comments. Much attention was paid to the layout and readability of the brochure.

The information about normal forgetfulness and dementia is clarified by several examples and carefully selected case descriptions, such that readers can recognize themselves in one or more of them. The text and case descriptions enable people to work out whether their worries are unfounded or whether it might be sensible to seek professional help. Other topics discussed in the brochure include the working of memory, existing misunderstandings, and the dementia syndrome (onset, course, consequences, diagnosis, and prognosis of dementia; problems that might occur; etc.). A lot of attention is paid to the changes that occur in the working of the human memory with age. Subjects that are discussed are speed, concentration, planning, attention, and also the acceptance of getting older. Much emphasis is on the physical causes (e.g., certain medications, the use of alcohol, inadequate nutri-

tion, thyroid problems, vascular problems, eyesight problems, and hearing problems) and the psychological causes (e.g., stress, depression, life events, social inactivity, and lack of interest) of forgetfulness. Finally, some practical advice is given for coping with memory problems and forgetfulness in daily life.

METHOD

Recruitment of the Respondents

People were told of the opportunity to order the free brochure via two regional newspapers and regional radio broadcasts. They were also asked to cooperate in a research project. There appeared to be a great need for information: Within 2 weeks, 622 people in the region had ordered the brochure. Nationwide, 25,000 people ordered the brochure within 2 years.

Questionnaires

To assess the effects of the brochure, we administered two written questionnaires. In the first, completed 2 weeks before the brochure was sent, two research questions were investigated: What are the demographic characteristics of people who are interested in the brochure, and why do they want this information? The second questionnaire measured several independent variables: changes in worrying, attributions (the causes to which people ascribe their forgetfulness), consultation of the general practitioner, discussion of complaints within the social environment, change of memory-related behaviors, and the role of locus of control (the extent to which people think they can influence the functioning of their own memory). Locus of control is a subscale of the Metamemory in Adulthood (MIA, control scale) Questionnaire (Dixon, Hultsch, & Hertzog, 1988).

Cognitive Test Battery

We wished to determine whether the people who had been reassured by the brochure that they did not have to worry about dementia indeed did not and whether those who had been encouraged by the brochure to seek help had reason to do so. Thus we used a short cognitive test battery consisting of four standardized tests and the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) to

assess the direction of changes caused by the brochure. The four tests, with six parameters, are often used in clinical neuropsychology and measure the functioning of memory, interference susceptibility, mental speed, and the processing of complex information (Jolles, 1985).

People could choose to be tested at home or at the Maastricht Memory Clinic. Most were tested at home. If they wanted to, the participants could receive their test results and discuss them with a neuropsychologist. Criteria for participation in the test were established before the first questionnaire was sent.

Auditory Verbal Learning Test (AVLT; Lezak, 1983). This procedure was derived from the work of Rey (1964). The AVLT involves five presentations with free recall of a 15-word list. Two scores were used, learning ability (immediate recall) and consolidation in long-term memory (delayed recall).

Stroop Color-Word Test (Stroop, 1935). The Stroop Test measures the ease with which respondents can shift their perceptual set to conform to changing demands. Stroop I and II measure mental speed, and Stroop III is a measure of interference susceptibility. The standard version, with 100 words on each card, was used (Lezak, 1983).

Symbol Digit Modalities Test (SDMT; Smith, 1973). The reading subscale of the Symbol Digit Modalities Test (SDMT) was administered to measure the extent of complex information processing under time pressure (Smith, 1973).

Fluency Test. The Fluency Test was developed by Luteijn and van der Ploeg (1983) and gives an indication of the speed of retrieving information from the semantic memory. People have to give as many animal names as possible in 1 min.

MMSE. The MMSE is a cognitive screening instrument consisting of a series of short questions and tasks that measure memory, orientation, verbal performance, praxis, and concentration. A shortened version of the MMSE (Folstein et al., 1975) was used: The questions concerning orientation were left out, because most people were tested at home. As a correction, we added 5 points to the score, so the maximum score remained 30.

Criteria for Participation in the Test

The respondents were divided into four groups. Group 1 consisted of people who had been worried about dementia before reading the brochure and remained worried after reading it ($n = 26$). Group 2 consisted of people whose worry about dementia strongly decreased after they read the brochure ($n = 51$). Group 3 consisted of people who started to

worry about dementia after reading the brochure (n = 7). Group 4 consisted of people who had not been worried about dementia before reading the brochure and were still not worried after reading it (n = 26). Group 4 was matched with Group 1 for level of education. Matching for age was a problem, because the average age of Group 4 was higher than that of Group 1. To avoid bias of the results, we excluded from the study people who indicated that their forgetfulness had something to do with their use of alcohol, tranquilizers, or sleeping pills. In total, 110 people were selected who fulfilled all criteria. For various reasons, 6 people could not be tested. Eventually, 104 people were tested, 25 in Group 1 (mean age = 65 years), 51 in Group 2 (mean age = 67), 7 in Group 3 (mean age = 62), and 21 in Group 4 (mean age = 69).

Transformation to z Scores

To compare the different tests, we transformed all scores to z scores, using norm scores from previous research. Because the score for a test was determined by the age of the individual, we used z scores to correct for age differences. The average test score of a matching age group on a test was subtracted from the score for the same test of the battery and divided by the accompanying standard deviation (Lezak, 1983). The score on the MMSE was not transformed. We used the norm scores of Houx (1991) to transform the results of the AVLT and the Stroop Test to z scores. For the SDMT, we used the data of Centofante (Lezak, 1983), and for the Fluency Test (animal names), we used the results of Ponds, Bruning, and Jolles (1992). For the MMSE, we used a cutoff score of 23 to discern possible dementia from no dementia (Folstein et al., 1975).

RESULTS

Response and Demographic Characteristics

Of the 622 questionnaires, 537 were returned (response rate = 86%); 476 people (response rate = 89%) were willing to participate in the project. The response to the post-test questionnaire was 97%: 57% of the respondents were women. The mean age was 66 years: 3% of respondents were younger than 50, 65% were between 50 and 70, and 32% were older than 70. Of all respondents, 64% were married or living together, 8% were unmarried, 5% were divorced, and 23% were widowed.

TABLE 1 Concern about Forgetfulness before and after Reading the Brochure (n = 414)

	Pre-test			
Post-test	(Very) much concern: n = 140	Little concern: n = 240	Hardly any/no concern: n = 34	Total: n = 414
(A lot) less concerned	63%	72%	0	63%
Unchanged	32%	26%	100%	34%
A little more concerned	4%	2%	0	3%
A lot more concerned	1%	0	0	0

Concern about Forgetfulness

The question about concern about forgetfulness was answered by 414 respondents on both the pre-test and post-test questionnaires (Table 1). Sixty-three percent of the 140 respondents who had been worried (a lot) about their forgetfulness before reading the brochure said that their concern decreased substantially or disappeared after reading it. Approximately 3% of the 414 respondents became more worried after reading the brochure.

Table 2 lists the attributed causes of forgetfulness. The answers were structured and represent all possible physical and psychological causes of forgetfulness that were discussed in the brochure. People

TABLE 2 Causes of Forgetfulness Mentioned by the Respondents in the Post-test Questionnaire (n = 370)

Cause	% Yes	% No	% I don't know
Age	87	5	8
Stress and tensions	30	53	17
Poor hearing or eyesight	19	67	14
Little contact with other people	13	81	6
Not enough hobbies or activities	8	86	6
Use of sleeping pills and/or tranquilizers	5	88	7
A brain trauma (accident or cerebrovascular accident)	4	93	3
Use of alochol	3	87	10
Lack of variety in nutrition	2	89	9
Loss of a loved one	2	98	0
Beginning of dementia	1	78	21

could indicate more than one possible cause. Eighty-seven percent of the respondents mentioned age as a possible cause of their forgetfulness. Strikingly, 30% said that their forgetfulness had something to do with stress and tension. A relatively high percentage (21%) answered, "I don't know whether dementia has something to do with my forgetfulness." Ten percent were not sure whether their use of alcohol had something to do with their forgetfulness. Most people who were concerned about their memory were also bothered by their forgetfulness in daily life, although some people who were worried had no problems in their daily life. Pearson's product–moment correlation between concern and bother in daily life was 0.57 ($p < .01$).

Concern about Dementia

The question about concern about dementia was answered by 400 respondents on both the pre-test and post-test questionnaires (Table 3). Seventy-seven percent of the 99 respondents who had been worried (a lot) about dementia before reading the brochure said that their concern decreased substantially or disappeared after reading it. Approximately 3% of the 400 respondents became more worried about dementia after reading the brochure.

Among the people who were still worried about dementia after reading the brochure, 28% had a close relative who had dementia. (This percentage was 11% among people who felt reassured after reading the brochure.) Almost 50% of all 175 worried people described themselves as extremely forgetful and were afraid that this heralded the onset of dementia: 20% were extremely forgetful and had a close relative who had dementia; 17% were not forgetful but were afraid of becoming demented because one or more close relatives were demented; 13%

TABLE 3 Concern about Dementia before and after Reading the Brochure ($n = 400$)

	Pre-test			
Post-test	(Very) much concern: $n = 99$	Little concern: $n = 208$	Hardly any/no concern: $n = 93$	Total: $n = 400$
(A lot) less concerned	77%	56%	0	48%
Unchanged	23%	42%	90%	48%
A little more concerned	0	2%	8%	3%
A lot more concerned	0	0	2%	1%

were not forgetful, had no close relative with dementia, but were still afraid because of the severity of the disease. A chi square of 12.3 ($df = 1, N = 175, p < .001$) was obtained when these percentages were used in a 2 × 2 Dementia in a Close Relative (yes vs. no) × Extremely Forgetful (yes vs. no) matrix. The people who had demented relatives were less concerned about forgetfulness being a sign of dementia than the other respondents were.

Consultation of the General Practitioner

Thirty-six (8%) of all 450 respondents had consulted their general practitioner after reading the brochure to discuss their concerns and complaints. Seventeen had consulted their general practitioner because they thought their forgetfulness was abnormal, 8 people wanted an examination of their ears or eyes, 6 people wanted a referral to a specialist, and 5 people wished to discuss a possible limitation of their medication. Table 4 gives an overview of the results of all consultations.

TABLE 4 Motive for and Result of Consulting the General Practitioner ($n = 36$)

	Motive			
Result	Forgetfulness is abnormal	Eyesight/ hearing	Desire for referral to specialist	Limitation of medication
"Don't worry; it's your age"	10	7	1	3
Referral to a specialist	2	1	2	0
Change of medication	1	0	1	1
General advice	1	0	1	1
No information at all	1	0	1	0
Advice for memory training	1	0	0	0
Diagnosis of Alzheimer's disease	1	0	0	0
Total	17	8	6	5

Influence of the Social Environment

Seventy-two percent ($n = 124$) of all people who were still worried about possible dementia after reading the brochure and who also had a spouse had discussed their worries with their spouses after reading

the brochure. Forty-one percent (n = 167) of all people worried about dementia had discussed their worry with other family members. The spouses' responses were as follows: "It is nothing serious" (60%), "Consult your physician" (16%), "Wait a while" (21%), and "You are worrying about nothing" (3%). Other family members gave the following advice: "It is nothing serious" (72%), "Consult your physician" (15%), "Wait a while" (10%), and "You are worrying about nothing" (3%). An important conclusion was that in most cases an individual's concern about possible dementia was not shared by her or his spouse or social environment. Only 1 in 6 people were advised to consult their general practitioner.

Change of Behavior

Forty-three (10%) of 440 respondents indicated that they changed one or more behaviors that might have had an impact on the functioning of their memory after reading the brochure. People reported using less alcohol (n = 20), taking fewer sleeping pills and/or tranquilizers (n = 19), and changing their nutrition patterns (n = 10). Six of these 43 people had also consulted their general practitioners to discuss their memory complaints. No correlation was found between behavioral change and locus of control.

The Mini-Mental State Examination

The MMSE scores were normally distributed in all four groups (n = 104 for all four groups together). Three people scored below 24 (they all scored 23). An analysis of variance revealed significant differences among the four groups, F (3, 100) = 2.8, $p < .05$. Group 3 (more worried after reading the brochure) had the lowest mean score (26.3), followed by Group 1 (still worried a lot) (27.8). Group 4 (little or no concern) had the highest mean score (28.8), followed by Group 2 (less concerned after reading the brochure) (28.2). Although these results were consistent with expectations, the differences among the four groups were of little clinical relevance.

The Short Cognitive Test Battery

The four cognitive tests yielded six z scores: the immediate and delayed recall scores from the AVLT, the mean score on the Stroop I and II tests, the Stroop III score, the score on the Fluency Test, and the score on the SDMT. We calculated the median score of the six z scores to get an indication of the cognitive functioning of the four groups. An anal-

ysis of variance revealed significant differences in the scores on the test battery, F (3, 97) = 3.6, $p < .05$. Group 3 (more concerned after reading the brochure) and Group 1 (still concerned) performed significantly worse than Group 2 (less concerned after reading the brochure) and Group 4 (little or no concern). We also analyzed individual scores, using a median score of –1.28 of the six z scores as a cutoff: A lower score meant that the performance was worse than the 10th percentile of what could be expected for a certain age (Lezak, 1983). This was interpreted as a possible indication of a cognitive deficit. Our reason for using the median score was that we were investigating a global deterioration. One abnormal score, however, could already be an indication of a cognitive deficit. All results are presented in Table 5.

All 3 persons with a MMSE score lower than 24 also had a median score below –1.28. After reading the brochure, 1 of them was rightly not reassured, 1 person had rightly become more worried, and 1 person was inappropriately reassured. Furthermore, 15 of the 30 people with a poor test score were probably not rightly reassured. One person who was not concerned should have been concerned. Of the 74 people with good test results, 15 (20%) were still worried about possible dementia after reading the brochure and 3 had become more worried about dementia after reading the brochure. Of these 18 people, 8 had a close relative with dementia (father, mother, brother, or sister). Among the people (n = 36) who were rightfully reassured, 8 had a close relative with dementia. Although this difference was not statistically significant, χ^2 (3, N = 54) = 2.83, p = .11, anxiety that the disorder might be hereditary could explain their concern.

TABLE 5 Results of Cognitive Test Battery by Group (n = 104)

Test	Total	Group 1 (not reassured) n	Group 3 ([a lot] less concerned) n	Group 2 (more concerned) n	Group 4 (little or no concern) n
Mini-Mental State Exam					
Score ≤ 23	3	1	1	1	0
Score > 23	101	24	50	6	21
Cognitive tests					
Median ≤ –1.28	30	10	15	4	1
Median > –1.28	74	15	36	3	20
Total	104	25	51	7	21

From t tests, it appeared that several differences were present between the group that was rightly worried and the group that was inappropriately reassured. The latter group experienced fewer problems with their forgetfulness in daily life, t (28) = 3.0, $p < .05$, and were more often of the opinion that they could more or less influence the functioning of their memory, t (27) = 2.1, $p < .05$, which means that they had a higher internal locus of control than did the rightly worried group. Although the median test score was below the limit for these two groups, the inappropriately reassured group scored significantly better than did the rightly worried group (–1.7 vs. –2.6), t (28) = 3.2, $p < .05$.

Who Consulted the General Practitioner?

Twelve people from the tested group (n = 104) consulted their general practitioners after reading the brochure in order to discuss their memory complaints and concerns. Seven of these people were still worried about possible dementia, and 1 had become more worried. Four people consulted their general practitioners despite decreased concern. Of all people with poor test results (n = 30), 20% had visited their general practitioners after reading the brochure.

Who Received Correct Advice from Her or His Spouse?

Forty-three people tested had been given advice by their spouse about their concern about dementia. Of the 27 people with a good test result, 25 received correct advice from their spouse, namely, "Don't worry, it's nothing serious" or "Wait for a while." Only 3 of the 16 people with poor test results received advice to consult their physician. The other 13 people were told not to worry, because their forgetfulness was nothing serious.

DISCUSSION

A brochure on the differences between normal forgetfulness and dementia was developed and evaluated for people who worry about their diminishing memory. Why is information on this topic so important? Clear information might prevent people who worry unnecessarily from becoming depressed, losing quality of life, or ending up in a vicious circle. This might contribute to a significant saving for the health care system. On the other hand, structured information on this topic might stimulate people who have memory problems not due to normal forgetfulness to seek professional help. In some cases, problems can be

solved by proper treatment or medication. In case of an irreversible cause of forgetfulness, an early diagnosis is important (Verhey, 1993).

The first goal of this study was to assess the effect of a public education brochure about the difference between normal forgetfulness and dementia. It appeared that a large group of people became less concerned about their forgetfulness or about dementia after reading the brochure. Furthermore, 8% of all respondents consulted their general practitioners about their worries or complaints. About 10% changed one or more behaviors that could have been influencing the functioning of their memory. An interesting finding was that in most cases, a person's concern about possible dementia was not shared by her or his spouse and other family members.

The second goal of this research was to find out whether the effects of the brochure were in the right direction. A series of four cognitive tests in combination with the MMSE gave an indication of the cognitive functioning of the respondents at that moment. This short cognitive test battery was not meant as a diagnostic instrument for dementia, which requires information about someone's medical history and a more thorough neuropsychological and neuropsychiatric examination.

One hundred four people were tested with the short cognitive battery. Of these people, 30 had a poor test score, and of these 30, 16 were inappropriately reassured by the brochure that they did not need to worry about their forgetfulness. We do not mean to imply that these people are developing a dementia syndrome, only that their forgetfulness was probably caused by something other than normal aging. Seventy-four people had good test results, yet 18 of these people were still worried about their forgetfulness. Eight of these 18 had a close relative with dementia. Anxiety that the disorder could be hereditary is a possible explanation for their concern. Someone with a good memory at a given moment could be worried, with reason, because of a hereditary defect. However, among experts there is still unclarity about this topic.

People with poor cognitive test results should have sought professional help in order to find out the causes of their current cognitive problems and yet were reassured after reading the brochure that their forgetfulness was not a problem. This result was not in accordance with the goals of the brochure. A possible explanation for this could be the fact that these inappropriately reassured people experienced fewer problems in daily life as a result of their forgetfulness than did people who were rightly worried. This group was also characterized by a higher internal locus of control. Because of this, they might have had a better way of coping with their forgetfulness in daily life. Another possibility is that they compensated for their memory problems, with the result that their subjective hindrance was low.

In composing the test battery, we chose tests that are described in the literature as sensitive predictors of cognitive deficits. The four tests were weighed equally. It could be argued that the AVLT, as the only real memory test, should have had a higher weighing factor. The use of cognitive tests to check the effects of public information about normal forgetfulness and dementia appears to be an appropriate method and could be used again in future research. In this study, the distinction between a good and a poor test score was used as an indication for justified and unjustified concern about dementia. Besides this, there might have been other reasons, for example, genetic predisposition, why people with good test results were rightly worried. It should also be noted that a dementia syndrome does not always begin with cognitive deficits. Problems might also occur in an affective way (e.g., dysthymia or mood swings).

On the basis of the results, we conclude that a systematically planned information brochure on the differences between normal forgetfulness and dementia can make an important contribution to reducing people's anxiety about dementia. However, in about one third of all people tested, the effects of the brochure were not in accordance with its goal. People who might have had a cognitive problem were reassured and people with good test results were still worried. Not all people who were rightly worried felt the need for professional help. At this point, the social environment could play an important role. In the next edition of the brochure, more attention will be paid to the contribution of the social environment. Another possibility is to develop a separate brochure for people who are worried about someone in their social environment.

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